

National Family Caregiver Support Program Resources

Caring for Someone in the Last Years of Life



Introduction

Helping to care for someone who may be nearing the end of his or her life can be a surprising, challenging, and rewarding experience. Whether you are a friend, family member, loved one, co-worker, or paid caregiver, the care that you provide does make a difference.

The last years of life are a time of many changes. The changes taking place in the life of the person for whom you care may raise questions and concerns about how best to meet their needs. Information and support is available. Your local hospice can help you understand and prepare for these changes.

When To Consider Calling Your Hospice:

- When you have questions about what to expect physically, emotionally and spiritually as the end of life approaches
- When you need information about resources that can help you manage your responsibilities as a caregiver
- When you have questions about how to have sensitive conversations about treatment choices, living arrangements, and personal care
- When you want help with preventing and managing symptoms related to an illness or its treatment
- When you want guidance in finding the opportunities for hope, comfort, and meaning that are part of this important time of life
- When you are experiencing feelings of loss, sadness, or grief associated with the illness or death of a loved one

Hospice Programs Can Offer You:

- Support as you make decisions about treatments and options for care
- Information about advance directives, such as living wills, that can help communicate choices about care
- Medical treatment that aggressively seeks to prevent, assess, and treat symptoms of discomfort and disease progression
- Comfort-focused (palliative) care provided by coordinated teams of professionals that include nurses, home health or certified nursing aides, social workers or counselors, chaplains, physicians, and trained volunteers
- Care that is guided by your goals and priorities
- Bereavement support to help you find comfort and hope

Hospices serve their communities by being a resource for meeting end of life needs. You can rely on your hospice for help in dealing with the practical, physical, emotional, and caregiving issues that are part of the last years of life. Hospice is not about giving up. It is about comfort, well-being, and quality of life. Anytime you need information from an experienced team of caregivers, contact your local hospice. They are here to help.

For more information about hospice and palliative care services in your community, call The National Hospice and Palliative Care Organization (NHPCO) Helpline at 1-800-658-8898 or visit the NHPCO web site at www.nhpco.org.

Planning Ahead

Information Gathering:

It can be difficult to focus on finding information and making plans related to financial, legal and healthcare matters and after-death responsibilities. Find this information before it is needed can help you better prepare for more difficult times.

Pre-Planning and Advance Directives

- Living will (indicates end-of-life care wishes)
- Health care surrogate (person designated to make health care decisions)
- Power of Attorney (document indicating who can make financial decisions for another person)

Identification

- Birth certificate (needed for death certificate).
- Social Security number (needed for death benefits)
- Marriage license
- Guardianship papers (Indicates who can make decisions for a person who cannot make decisions.)
- Insurance policies
- VA claim number or honorable discharge certificate (important for getting death benefits)

Affiliations

- Social or religious (for notification purposes and obituary preparation)
- Family, friends, clergy, business associates (phone, address to notify of death or change of condition)
- Education and military service (for preparation of obituary)

Financial

- Banking accounts, CDs, IRAs, money market accounts, credit union, trust pensions, 401K plan, Insurance policies (location and account numbers)
- Annuities, stocks, bonds (location and account numbers)
- Safe deposit box (location of box and key)
- Last will/testament, attorney/executor contact information
- Loans, credit cards (list where to send, when, amount of payment)
- Income tax records
- Mortgages, lease and rental information
- Location of family treasures, jewelry
- Certificate of ownership for property (keys for each)

Funeral/Memorial Planning:

Knowing your loved one's wishes and preferences for the funeral services will make it easier to plan and may ease the burden on those who survive. The funeral is a celebration of the life of the deceased and ceremony for those who survive and grieve. The funeral service is one place to express your pain and share your memories.

Types of Funeral Services

- Traditional – visitation and service in which the deceased is present in an open or closed casket
- Memorial – service without the presence of the deceased
- Graveside – service held at the graveside prior to burial
- Direct – the deceased is buried, cremated or donated to medical science without any service

Funeral Home Information

- Name, location, phone number of funeral home
- Place of burial

Care of the Deceased

- Open or closed casket – at formal visitation and/or at funeral service
- Private family viewing only
- Clothing, jewelry, items to be placed in casket

Filings and notices

- Death certificates – can be provided by funeral director, additional copies obtained through Bureau of Vital Statistics
- Obituary – may include names and location of survivors, service record, special achievements, religious affiliation, education history, date, time and location of funeral service and designation of tributes (to charity or organization)

Funeral Services

- Date, time, location of service, visitation, wake
- Clergy presiding
- Pallbearers
- Preferred music – requested performers
- Readings – poems, scriptures
- Eulogy or speakers
- Family, friends to be included in the service
- Flowers
- Memorial displays – photographs

Information provided in this fact sheet was adapted from materials submitted by The Hospice of the Florida Suncoast. For more information visit their website: www.thehospice.org.

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov